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Validation of a Unique Measure of Physical Carer Demand in Parents of Physically Disabled Children – A Pilot Study

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Abstract

Background: There is scarce epidemiology of low back pain [LBP] in parents of physically disabled children. Whilst it has been suggested that physical stress related to carer-related duties may be a risk factor for LBP in this parent group, and may explain the reported high prevalence of LBP, no known instrument presently measures this. Subjects and Purpose: Following a review of relevant carer literature, a survey instrument measuring aspects of physical carer demand was designed (Parent-Specific Physical Carer Demand Measure [P-S PCDM]) using existing and new instrument items and targeted response categories. It was tested for validity and sensitivity on a small number of parents of physically disabled children between the ages of 5 and 12 years. Results: The instrument had face, content and construct validity, as parents believed that it encompassed the range of important physical issues that they dealt with regularly, and that the response categories were sufficiently distinct to distinguish between children with different carer needs. Conclusion: The instrument provides a specific mechanism to measure physical carer burden in young disabled children. Future research using the instrument with larger and more heterogeneous samples is required to test the reliability, validity and sensitivity of the instrument.

BACKGROUND

There is a paucity of research pertaining to the epidemiology of low back pain [LBP] in parents/caregivers of physically disabled children.¹⁻³ The available research has methodological shortcomings in terms of limitations to sample size and selection, and measurement validity, yet nonetheless it suggests that LBP is a considerable problem within this group, irrespective of the age of the disabled child. Not only can LBP impair day-to-day quality of life, but it may also negatively impact on parents' and caregivers' ability to care for their physically disabled children, who may depend on parental assistance to perform daily activities.

The multi-factorial risks for developing LBP, encompassing both physical and psychosocial aspects, are extensively documented for the general population.⁴⁻¹⁰ However, the comparatively higher prevalence of LBP reported in the limited literature pertaining to parents of physically disabled children warrants further investigation into the specific risks to which this

group are exposed.¹⁻³ This literature suggests that caring for a physically disabled child presents specific risks, particularly in relation to providing physical assistance to the child. This theory of increased risk exposure potentially accounts for the high prevalence of LBP reported within this group.

Devising a survey instrument

In unpublished work, Ward explored LBP in carers/parents of children aged less than five years.³ The specific needs of carers of young disabled children were considered in a purpose-built but non-validated instrument. We were interested in the experiences of carers of older children aged 5-12 years (who would have a range of body sizes, physical capacities and physical needs), and thus we reviewed the literature pertaining to surveys of carers of disabled older children, young adults or older adults, to identify any available survey instrument suitable for use to assess the physical burden on these carers.¹¹⁻¹⁸ We defined the physical caregiver burden in this instance as the physical stress placed on the parent of the child with the

physical disability, owing to caring activities. These have particular relevance to the child's functional limitations, as a parent may exert regular and considerable physical effort when assisting the child with daily activities such as bathing, transferring and feeding.

Our review of existing measures of 'caregiver burden' or 'demand' measures identified several instruments. However, the literature on 'caregiver burden' or 'demand' related mostly to the elderly population, particularly carers of people with dementia or cerebrovascular accident ('stroke').¹¹⁻¹⁸ No instrument specifically measured aspects of physical carer demand. Subjective rating of overall burden, or emotional distress, was most common, with few direct attempts at quantification of physical exertion in the carer role.^{11-13,15-18} Where aspects of physical care were assessed, these domains were often incomparable with those of caring for physically disabled children, due largely to the vastly different population to whom these instruments were administered (ie carers of cancer patients).^{11,13,17} Whilst many of the instruments have demonstrated validity in their tested populations, far less is known about their reliability and sensitivity.^{11-13,17,18}

Consequently, in the limited literature pertaining to parents of physically disabled children aged 5-12 years, we identified no standard method for quantifying the demands on physical carers/ caregivers, and we found no other suitable survey for carers of other disabled people which could be adapted to suit the specific needs of carers of this group. If LBP is indeed a problem for these carers, then further investigation should be made of this phenomenon, as maintaining the health of carers would appear to be essential in terms of their own quality of life, the quality of care provided for their child, and the burden on society should parents not be able to continue with these caring activities. Standardized measurement of aspects of this phenomenon, in conjunction with standard prevalence measures of LBP, would better inform understanding of the LBP epidemiology of parents caring for physically disabled children.

We drafted an instrument that attempted to measure standard aspects of the physical carer demand in parents of 5 to 12 year old children with a physical disability, and we investigated the content and construct validity of this instrument. The developmental processes of the instrument (Parent-Specific Physical Carer Demand Measure [P-S PCDM]) are described in this paper. The P-S PCDM was designed for use with reliable and valid measures of LBP prevalence and severity, such as the Nordic Low Back Questionnaire or the Oswestry Disability Index, to quantify specific risks for LBP in parents/carers of children aged 5-12 years with a physical disability.¹⁹⁻²¹ It should be stressed that the P-S PCDM, in isolation, does not aim to assess a parent's risk for developing LBP. Rather, its use is in LBP risk factor studies to quantify potential risk factors, which are then assessed for significant association with LBP, to facilitate our understanding of why parents of physically disabled children experience LBP.

Methods

Ethical Approval

Approval for this study was obtained from the University of South Australia Divisional Human Research Ethics Committee and the Novita Children's Services [Novita] Clinical Research Committee. Novita is a South Australian therapy and support service for physically disabled children aged up to 18 years and their families.

Construction of Instrument

The Parent-Specific Physical Carer Demand Measure [P-S PCDM] was constructed to quantify the multi-factorial nature of caring for a disabled child, thus it collected information on the child, the parent and their caring situation. The instrument did not attempt to incorporate measures of psychosocial demands, which may influence both the development and experience of LBP. This decision was made because of the range of instruments already available which could be used to measure these constructs. The P-S PCDM collected age and weight of the physically disabled child, the functional limitations of that child with regard to daily activities, the nature of assistance provided by parents to the child to assist them in daily activities, the relative time demands on the parent and whether additional carer assistance was received. Questions regarding additional children and past history of LBP were also included. The instrument items were either developed by the research team or modeled on Ward.³ Response categories needed to be sufficiently sensitive to gauge both the functional limitation of the child and level of parental assistance provided. Given the lack of suitable response categories in published surveys, a new scoring system was devised.¹¹⁻¹⁸ Responses to each functional task were incorporated into a single question through the use of a table (see Appendix 1).

Validity Testing

Research Design

Qualitative research using semi-structured interview questions delivered over the telephone or face-to-face, was used to test face, content, and construct validity of the instrument.²²

Subjects

Ten parents of children between 5 and 12 years of age with a physical disability were sampled from Novita's client database. Parents were purposefully sampled by the level of their child's disability to ensure the instrument was tested across a spectrum of disability. The level of child disability was determined by one of the researchers (SG) in consultation with Novita clinical staff. The Novita parent sample was supplemented by two registered practising physiotherapists, who also were parents of children with a physical disability between 5 and 12 years of age. These parents worked in the same institution as the research team, and provided an additional validation arm to the study. One physiotherapist's child was registered with Novita. The physiotherapist parents' responses were considered separately to the other parents, as it was envisaged that due to their potentially greater knowledge of biomechanics, they may identify theoretical caring situations,

as well as those actually experienced with their child, compared with parents who potentially spoke only about their individual situation.

Procedure

The survey instrument (P-S PCDM), along with introductory letters detailing the purpose of the study and roles of the parents, consent forms and reply paid envelopes addressed to the primary researcher, were mailed to subjects' postal addresses. The two physiotherapist parents were contacted directly regarding participation in the study. In the mail-out, parents were asked to specify appropriate times and mechanism for contact.

Parents responding to the survey request were consequently contacted by the primary researcher at times specified in their returned consent forms, and by telephone, the medium they all preferred. The two physiotherapists were interviewed face-to-face by the primary researcher, as this was their preferred method of contact.

All interviews were conducted as semi-structured conversations that addressed key questions, while allowing for elaboration of participants' ideas. Questioning was designed to examine both the face and content validity of the instrument, and specifically the construct validity and response categories of the functional limitation table (Question six, Appendix 1). The line of questioning undertaken in the interviews is outlined in Table 1 (Results).

Data Management and Analysis

Written notes were taken of the participants' responses by the primary researcher in all interviews, and then collated for analysis. Analysis of key themes in individual responses, and consistency of themes between responses was undertaken independently by the research team members (M.P., K.G-S., S.G.), with subsequent collective discussion of themes amongst the same members used to reach a consensus opinion. Changes to the instrument items and/or response categories were identified on this basis.

Results

Subjects

Six subjects participated in this pilot validation study (four Novita parents (40% mailout response) and two physiotherapist parents (100% response). The Novita parents reflected four females, and the physiotherapists were both male. No response was obtained from the other six Novita parents.

Responses

Subject responses regarding questionnaire design, layout, content, question wording and response categories were generally positive, with consensus occurring on many issues (see Table 1). Only a small number of issues were raised, and issues were not consistently raised by participants.

Barriers to instrument completion

The only identified barrier to instrument completion was extrinsic to the instrument, where parents of physically disabled children believed they formed a potentially over-researched group that may be disinclined to respond to frequent survey requests.

Instrument content

All subjects considered that the wording and layout of the instrument was appropriate and readable. Further physical issues involved in caring for physically disabled children pressure care were identified as pressure care, play, and social activity. With respect to pressure care, the act of repositioning the child, identified by parents as the physically intensive component of the task, was considered to also relate to the existing 'transfers' heading, and thus a separate item was not created. Whilst parents may exert considerable physical effort when assisting their child in play and social activity domains, the demands on the parent were considered to be largely dependent on the interests of the child, as well as that child's functional limitations. Furthermore, the instrument placed most emphasis on essential care tasks, to which play and social activity may not add further information. Accordingly, the items of play and social activity were deemed not to warrant inclusion in the instrument.

Ambiguity was identified regarding the secondary part of Question one, which asked for perceived causality of LBP. LBP is a multi-factorial phenomenon, thus inferring causality may be problematic, particularly as LBP may stem from interactions between exposures.⁴⁻¹⁰ Previous history of LBP is also a risk for future episodes, which may confound any responses to this question.²³⁻²⁵ Consequently, the secondary part of this question was removed from the revised instrument.

Response categories

The categories of the functional limitation table (Question six) comprised a five-point scale ranging from classifying the child as fully independent to one who did not perform any part of the task. All subjects perceived sufficient distinction between response categories. Whilst one subject identified that category 1 did not explicitly state that no physical assistance was provided by the parent, this distinction was implicit with respect to the other response categories. However, it was apparent from discussions that the initial example activity 'bike riding' was not an appropriate example for the 'mobility' heading, as it required potentially higher order motor skills than simple ambulation and essential mobility. One subject identified that the level of assistance provided to her child varied on what she described as 'good' and 'bad' days, and thus her responses may fluctuate depending on day of testing. However, her attention was drawn to the instruction to rate the child 'on average', to which the subject concluded she would be able to answer the question readily. The final revised version of the instrument is presented in Appendix 2.

Table 1 – Interview Questions and Summary of Responses

Question	Consensus agreement (all subjects)	Problematic issues raised during interview
Does the questionnaire encompass the most important physical issues dealt with by parents?	N: Yes	PT: Identification of pressure care & play/social activity as tasks requiring parental assistance
Is the functional limitation table easy to understand & complete?	PT: Yes	N: Different levels of assistance needed to be provided to the child
Are the functional limitation response categories sufficiently distinct?	N: Yes PT: Yes	PT: Category 1 did not implicitly state no physical assistance given
Any perceived barriers to response?	PT: Yes (No barriers)	N: Barriers to response extrinsic to survey instrument
Is the questionnaire, as a whole, simple to understand and complete?	N: Yes PT: Yes	-
General comments and suggestions	-	N: Q1 – different episodes of LBP may vary in perceived cause PT: - Psychosocial aspects not addressed - Parents may receive occasional respite care - Child height data not collected
Key: N = Novita parents PT = Physiotherapist parents		

Discussion

This is the first known instrument which quantifies factors contributing to the physical carer demand specific to parents of children with a physical disability aged between 5 and 12 years. Construction of the instrument was based on two premises; that specific physical factors were encountered in carer-related duties, including the physical assistance provided to the physically disabled child, and that these factors are potentially related to LBP episodes in the parent.^{1,3,5,8-10}

When constructing and modifying the instrument, it was important that due consideration was given to the impact of implementing changes affecting questionnaire length, as longer questionnaires are associated with decreased response rates.²⁶ The final instrument takes no more than two sides of one A4 sheet, and approximately 2-3 minutes to complete. Its language is appropriate for literate adults within minimal schooling. Given the consistent nature of physical activities undertaken by parents/caregivers of disabled children, the instrument could have international relevance.

The instrument appeared to adequately address the range of day-to-day carer-related physical issues experienced within this parent group. The purposive sampling, which allowed for a wide range of child disability/physical limitation, and the additional validation arm of two experienced physiotherapist parents, suggests that the instrument is widely useful for research into disabled children's carers' LBP. Furthermore, saturation of interview information was reached on several questions prior to completion of the six interviews, which represents a measure of adequate validity of instrument

construction.²² Considering parent concerns related to pressure care, play and social activities, no new items were created, as repositioning the child for pressure care was considered to relate to the existing 'transfers' heading, and social activities/play were more related to the individual child's interest and physical limitations. Given one subject's lack of awareness as to the relevant time period when rating their child's functional limitation, further attention was drawn to the instructions by increasing the font size to Times New Roman 14, and utilising bold type in the revised instrument (see Appendix 2).

The point that some parents may receive occasional respite care was not previously considered during instrument development. The instrument endeavours to elicit information regarding 'average caring conditions,' and thus receipt of occasional respite care represented an exceptional situation and would not substantially reduce the physical carer demand. Provision for child height data, allowing calculation of body mass index was also not included. Whilst BMI of the physically disabled child is reportedly associated with parental LBP, it may not readily be known or measured by parents. Child weight is considered in the literature to be of equal or greater importance than BMI, given the physical load it creates on the parent when providing physical assistance.²

Whilst the situation did not arise during the interviews, it was hypothesised that situations may exist where subjects may have an additional disabled child not registered with Novita, such as those with an intellectual disability or not otherwise meeting Novita eligibility criteria. It was likely that these children would be receiving higher levels of parental care than non-

disabled children, which was important to establish if data was to be analysed against LBP prevalence measures to establish associations with putative risk factors. Thus, provision was made on the instrument to denote any additional disabled children in the family who were not registered with Novita.

Whilst the instrument is believed to have appropriate validity from this small pilot study, the small number of participants in this pilot study precludes us making a broad statement regarding wide instrument applicability. Other issues related to caring for a physically disabled child may have been overlooked by the developers and the parents. Furthermore, reliability of responses to the instrument is unknown. Further research into instrument validity and reliability, along with potential application with different parent groups, is required.

Conclusion

To be able to identify parents/caregivers with high-risk of LBP relating to high physical caring demands would support higher

quality epidemiological research, as well as development of strategic interventions to improve spinal health in this target group.

The findings from this study suggest that the P-S PCDM demonstrates promising content and construct validity for use with parents of physically disabled children aged between 5 and 12 years. Thus this instrument provides a first small step by attempting to quantify potential physical risk factors for carer LBP. Whilst this instrument was designed primarily for use with parents of physically disabled children between the ages of 5 and 12, it potentially has application for parents of physically disabled children of other age groups. Given the distinct nature of the response categories, we also believe that with minor modifications to the listed examples and wording, the functional limitation table is potentially applicable within other carer populations, including carers of geriatric populations.

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APPENDIX 1 – Preliminary Version, P-S PCDM Questionnaire

Q1. Have you had any low back pain before the birth of your child?

Yes No (Select one)

- If yes, what do you believe is the cause of your back pain?

Q2. Could you please provide the following information about your child that is registered with Novita:

<i>Age</i>	<i>Weight (approximate)</i>	<i>Gender</i>
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F

Q3. Do you receive help from an additional carer outside the immediate family, paid or otherwise?

Yes No (Select one)

- If yes, with what specific tasks?

Washing/Dressing child

Feeding child

Carrying/lifting/transporting child

Other (please specify) _____

Q4. On a normal weekday, does the child that is registered with Novita attend school?

Yes No (Select one)

If you answered no, how much time does this child spend at home with you? (Please tick one)

0 – 3 hours

3 – 6 hours

6 – 12 hours

Full-time

Q5. On a normal day on the weekend, how much time does the child that is registered with Novita spend with you? (Please tick one)

0 – 3 hours

3 – 6 hours

6 – 12 hours

Full-time

Please turn over...

Q6. The following table is being used to find out what difficulties your Novita-registered child has with several every-day tasks. For each task listed, *on average during normal school time*, please rate your child’s abilities by ticking the most appropriate response from the following categories:

- 0:** Child is either fully independent doing the task, or needs no more assistance than a non-disabled child of the same age.
- 1:** Child can typically perform the task, but requires more supervision, additional time, or verbal prompting from parent/carer than would be required for a non-disabled child of the same age.
- 2:** Child can do a considerable amount of the task themselves, but requires some physical assistance from parent/carer, in addition to any supervision or prompting.
- 3:** Child can only do a small part of the task at most, and requires maximum physical assistance from parent/carer, in addition to any supervision or prompting.
- 4:** Child does not perform any part of the task, rather aids or devices are used to complete the task. *An example of this is a child who is tube-fed, or transfers using a mechanical hoist device.*

Please tick one response for each task

	0	1	2	3	4
Transfers eg getting in & out of bed, car					
Self care tasks eg dressing, showering/bathing					
Mobility eg walking, wheelchair, bike-riding					
Mealtimes eg cutting food, swallowing, self-feeding					

Q7. Could you please provide the following information for any other children that are NOT registered with Novita:

<i>Age</i>	<i>Weight (approx.)</i>	<i>Gender</i>	<i>Attends School/ daycare on a regular basis?</i>	
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F	<input type="checkbox"/> Yes	<input type="checkbox"/> No
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F	<input type="checkbox"/> Yes	<input type="checkbox"/> No
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F	<input type="checkbox"/> Yes	<input type="checkbox"/> No
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F	<input type="checkbox"/> Yes	<input type="checkbox"/> No

APPENDIX 2 – Revised Version, P-S PCDM Questionnaire

Q1. Have you had any low back pain before the birth of your child?

Yes No *(Select one)*

Q2. Could you please provide the following information about your child that is registered with Novita:

<i>Age</i>	<i>Weight (approximate)</i>	<i>Gender</i>
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F

Q3. For this child, do you receive help from an additional carer outside the immediate family, paid or otherwise?

Yes No *(Select one)*

- *If yes, with what specific tasks?*

- Washing/Dressing child
- Feeding child
- Carrying/lifting/transporting child
- Other (please specify) _____

Q4. On a normal weekday, does the child that is registered with Novita attend school?

Yes No *(Select one)*

If you answered no, how much time does this child spend at home with you? (Please tick one)

- 0 – 3 hours
- 3 – 6 hours
- 6 – 12 hours
- Full-time

Q5. On a normal day on the weekend, how much time does the child that is registered with Novita spend with you? *(Please tick one)*

- 0 – 3 hours
- 3 – 6 hours
- 6 – 12 hours
- Full-time

Please turn over...

Q6. The following table is being used to find out what difficulties your Novita-registered child has with several every-day tasks. For each task listed, *on average during normal school time*, please rate your child's abilities by ticking the most appropriate response from the following categories::

- 0:** Child is either fully independent doing the task, or needs no more assistance than a non-disabled child of the same age.
- 1:** Child can typically perform the task, but requires more supervision, additional time, or verbal prompting from parent/carer than would be required for a non-disabled child of the same age.
- 2:** Child can do a considerable amount of the task themselves, but requires some physical assistance from parent/carer, in addition to any supervision or prompting.
- 3:** Child can only do a small part of the task at most, and requires maximum physical assistance from parent/carer, in addition to any supervision or prompting.
- 4:** Child does not perform any part of the task, rather aids or devices are used to complete the task. *An example of this is a child who is tube-fed, or transfers using a mechanical hoist device.*

Please tick one response for each task

	0	1	2	3	4
Transfers eg getting in & out of bed, car					
Self care tasks eg dressing, showering/bathing					
Mobility eg walking, wheelchair					
Mealtimes eg cutting food, swallowing, self-feeding					

Q7. Could you please provide the following information for any other children that are NOT registered with Novita:

*(If any of these children have a disability, please mark with an *)*

<i>Age</i>	<i>Weight (approx.)</i>	<i>Gender</i>	<i>Attends School/ daycare on a regular basis?</i>	
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F	<input type="checkbox"/> Yes	<input type="checkbox"/> No
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F	<input type="checkbox"/> Yes	<input type="checkbox"/> No
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F	<input type="checkbox"/> Yes	<input type="checkbox"/> No
_____ yrs	_____ kgs	<input type="checkbox"/> M <input type="checkbox"/> F	<input type="checkbox"/> Yes	<input type="checkbox"/> No